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Evaluation of a psycho-educational group intervention for children treated for cancer: a descriptive pilot study

Heleen Maurice-Stam[1]*, Lobke M. Silberbusch[1], Bob F. Last[1,2] and Martha A. Grootenhuis[1]
[1]*Psychosocial Department, Emma Children's Hospital, Academic Medical Center, Amsterdam, The Netherlands*
[2]*Department of Developmental Psychology, Vrije Universiteit Amsterdam, The Netherlands*

**Correspondence to: Paediatric Psychosocial Department, Emma Children's Hospital, Academic Medical Center, G8-224, PO Box 22700, 1100 DE Amsterdam, The Netherlands. E-mail: h.stam@amc.uva.nl*

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Abstract

***Objective*: The present paper reports about the content and evaluation of a psycho-educational group intervention for children growing up with a history of cancer, *Op Koers Oncologie* (OK Onco). OK Onco is aimed at empowerment of survivors of childhood cancer by teaching disease-related skills. The purpose of this pilot study is to evaluate whether OK Onco was appropriate for use among paediatric survivors of childhood cancer.**

***Methods*: Eleven participating children and their parents completed questionnaires about the disease-related skills that were taught in the intervention, before the intervention and 0–4 weeks after the intervention. In addition, parents were interviewed in focus groups.**

***Results*: Positive outcomes were found on most items concerning disease-related skills. Remarkable improvements were found with respect to the intervention goals 'social competence' and 'positive thinking'. The parents reported that sharing emotions and experiences with other survivors of childhood cancer was an important element of the OK Onco program, which underscores the benefit of a disease-specific program for cancer survivors.**

***Conclusions*: In conclusion, the results of the pilot study indicate that OK Onco is appropriate for paediatric survivors of childhood cancer. Implementation of the intervention is the next challenge.**

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Keywords: group intervention; childhood cancer; psychological; coping strategies; survivors

Background

The treatment of patients with childhood cancer has enormously improved in recent decades. The overall five-year survival rate for children diagnosed with cancer in Europe is currently more than 70%, as compared with 30% in the 1960s [1,2]. As a result, many patients who may previously have had a limited life expectancy are now growing up with childhood cancer and surviving into adulthood. The other side of these promising developments, however, is that many survivors of childhood cancer have to live with adverse effects of the disease and treatment, and with an increased risk of developing subsequent neoplasms [3]. Research on specific areas of psychosocial adjustment showed that between 25 and 30% of survivors experience personal, family or social difficulties that affect their academic achievement, employment, interpersonal relationships or self-esteem [4].

Considering the adverse effects of many treatments, the uncertainty about the further course of the disease and other psychosocial implications of childhood cancer, there is need for disease-specific interventions for survivors of childhood cancer. The current paper reports about the content and evaluation of a psycho-educational group intervention for children growing up with a history of cancer, *Op Koers Oncologie* (OK Onco). OK Onco is aimed at empowerment of survivors of childhood cancer by teaching disease-related coping skills. The main purpose of the study is to evaluate whether the OK Onco program is appropriate for paediatric survivors of childhood cancer and to get a first impression of the effectiveness of the intervention.

Intervention

Psycho-educational group interventions are used in a variety of paediatric populations. The focus of group interventions is on emotional support, improving adaptation and specific skills and reduction of physical symptoms by behaviour change. Overall, there is evidence that psycho-educational interventions for children with a chronic disease that incorporates cognitive-behavioural techniques, have positive effects on

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Table I. Description of the sessions OK Onco

Session	Content	Homework
1	Introducing the intervention and rules Getting to know each other Making a name for the group Thermometer Introducing TFD-model+SoF	Three questions about your disease
Start every session	Questionnaires Thermometer Nice and new last week Discussion of homework	
2	It is good to know better How can you find answer to a question? Relaxation exercise	Formulate two questions and find answers Relaxation exercise (CD)
3	Video practicing tricks for medical procedures Visit of the oncologist Relaxation exercise	Find two examples how you can relax Write the answers of the doctor in workbook
4	My personal competencies game Video: take initiative and inform Role play: active approach	Formulate two things you can not do and two things which you can do instead
5	Teasers and pleasers game Recognition of negative and positive thoughts Role play: inform peers about what you can not and what you can do instead	Create a list of all you are able to do Relaxation
6	Drawing: personal competency Making compliments Evaluation	

social-emotional outcomes such as self-efficacy and psychosocial well-being [5–8].

The Psychosocial Department of the Emma Children's Hospital AMC set the first steps toward a Dutch evidence-based psycho-educational intervention aimed at the empowerment of children and adolescents with a chronic disease by teaching active use of coping strategies. A standardized intervention, called *Op Koers* (OK), was developed based on Beck's cognitive theory [9,10] and the cognitive behaviour therapeutic approach that integrates behavioural procedures such as modelling, contingency management, exposure exercises and cognitive techniques [11]. The main goals of the OK program concern: (1) Information seeking and information giving about the disease; (2) Relaxation; (3) Social competence; (4) Positive thinking. For the description of the goals, we refer to the section Results and intervention goals. Children growing up with a history of childhood cancer might have needs and problems different from those growing up with other diseases. Some cancer-specific elements were therefore added to the OK program for use among paediatric survivors of childhood cancer: *Op Koers Oncology* (OK Onco) (Table 1).

Evaluation

Recruitment and participants

Paediatric survivors of childhood cancer visiting primary school were recruited from the outpatient clinic of the Emma Children's Hospital Academic Medical Center in Amsterdam. The inclusion criteria were: (1) 8–12 years; (2) 1/2–6 years after completion of successful cancer treatment; (3) not attending a school for seriously mentally retarded children.

After permission of the oncologist, 56 consecutive children were invited to take part in the intervention by a letter along with an entry form. Written consent was asked from the parents of the participating children. A total of 11 children (20%) participated in the OK Onco program, six boys and five girls. One boy was excluded from analysis because he attended less than three of the six sessions. Diagnoses were ALL ($N = 4$), Wilms tumour ($N = 2$), AML ($N = 1$), Burkitt lymphoma ($N = 1$), rhabdomyosarcoma ($N = 1$) or brain tumour ($N = 1$). Time since end of cancer treatment varied from 1–6 years.

Measurement and analyses

Disease-related skills were evaluated with the *Questionnaire Op Koers* (*QOK-child*, *QOK-parent*) [8] and the *Cognitive Control Strategies Scale* [12] that children and their parents were asked to complete before (*T*0) and 0–4 weeks after (*T*1) the intervention. In addition, the intervention was discussed in focus groups with parents during the last session of the intervention.

To evaluate the effect of the intervention, the individual answers on the items before the intervention (*T*0) were compared with those after the

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Table 2. Intervention goals before and after the intervention

	Positive outcome[a]			Negative outcome[b]
	Tot	Up	Equal	Tot
Information seeking and giving about the disease				
I know how to get an answer on questions concerning my disease	8	2	6	2
If I have a question about my disease, I know different ways to get an answer	9	6	3	1
If I have a question about my disease, I ask my doctor	6	2	4	4
If I have a question about my disease, I ask my parents	10	4	6	0
My child knows how to get an answer about his/her disease	8	4	4	1
Relaxation				
When I am nervous, I know how to relax myself	6	1	5	4
During a visit at the doctor, I get nervous	6	1	5	4
If others ask me questions about my disease, I get nervous	9	5	4	1
When I am at the doctor, I am able to relax	5	3	2	5
My child knows how to relax when he/she is nervous	5	3	2	4
Social competence				
I think it is hard to tell others about the things I am not able to do because of my disease	8	5	3	2
With my friends I talk about my disease	4	4	0	6
If I am unable to take part of an activity because of my disease, I tell my environment	7	1	6	3
I think it is hard to explain others about my disease	6	2	4	4
I am able to explain others about my disease	8	5	3	2
I know what I am capable of doing	10	6	4	0
My child knows the activities he/she is capable of doing	7	6	1	1
Positive thinking				
I think my future looks positive	10	5	5	0
When I think about my disease, I think everything will work out fine	9	1	8	0
I worry about my disease	9	4	5	1
If I have gloomy thoughts about my disease, I know what to do to feel better	7	5	2	3
My child feels happy about himself/herself	8	2	6	1

[a]Positive outcome: Tot: total amount of answers in the positive category at *T*1. Up: amount of people who answered in the negative category at *T*0 and positive category at *T*1, or whose answers improved (*T*1 compared with *T*0). Equal: amount of people who answered equal in the positive category at *T*0 and *T*1.
[b]Negative outcome: Tot: total amount of answers in the negative category at *T*1.

intervention (*T*1) in the following manner. First, the four answer categories of the *QOK-c*, *QOK-p* and *CCSS-CF* were dichotomized in a positive category and a negative category. Positive category being: (almost) always and often, or (totally) agree; negative category being: sometimes and (almost) never, or (totally) disagree.[1] Second, we determined whether the answers stayed equal, improved or decreased from *T*0 to *T*1. Finally, we labelled the change between *T*0 and *T*1 as 'positive outcome' or a 'negative outcome'. *Positive outcome* was defined as: (1) scores in the negative category at *T*0 and in the positive category at *T*1; (2) scores in the positive area at both *T*0 and *T*1. *Negative outcome* was defined as: scores in the positive area at *T*0 and in the negative area at *T*1; (2) score in the negative category at both *T*0 and *T*1. The results of the focus group were reported at the corresponding intervention goals.

Results and intervention goals

Information seeking and information giving about the disease

The children learned different ways to get and give information on their disease. They were encouraged to seek information because it is 'good to know better' and important to have realistic thoughts about their disease. The children were trained in telling the story of their disease.

The intervention goal is evaluated through five items (Table 2). Two to six children reported an improvement on one or more items from *T*0 to *T*1. The most favourable outcomes were reported on the item 'If I have a question about my disease, I know different ways to get an answer'. On the other hand, during the focus groups, a lot of parents reported that seeking information did not seem to be relevant for their children because that they have been treated long time ago and they wanted to get on with their life.

Relaxation

Relaxation was practiced through exercises that can be used in stressful (medical) situations. The children got a CD for use at home.

Five items concerned the intervention goal 'relaxation'. It is remarkable that all but one child had a positive outcome on the item 'If others ask me questions about my disease, I get nervous'; five of them improved from *T*0 to *T*1. For five children, however, it remained difficult to relax during a visit to the doctor. Uncertainty about recurrence of the disease could play a role.

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A good example of the use and benefit of relaxation techniques came from a mother in the focus group. At the end of the course, her son had to go to the hospital for an unpleasant medical seizure and for the first time the doctors did not need to give him valium. On the other hand, two parents reported that the relaxation-exercise was not useful because their child was not stressed.

Social competence

Social competence was taught by story-telling and group discussions about activities the child can do or cannot do because of the disease. Feelings of being different owing to the illness were discussed.

The outcomes on the seven items related to the intervention goal 'social competence' were diverse. Some results are very positive; half of the children reported an improvement from *T*0 to *T*1 on the items 'I think it is hard to tell others about the things I am not able to do because of my disease', 'I am able to explain others about my disease' and 'I know what I am capable of doing'. These results were affirmed by the answers of the parents. On the other hand, six children had negative outcomes on 'With my friends I talk about my disease' and four on 'I think it is hard to explain others about my disease'.

In the focus groups, almost every parent indicated that in future interventions, they would like to have extra attention for dealing with the world outside the hospital because their children did not realize how delicate the word cancer is in the society.

Positive thinking

Positive thinking was encouraged by identifying and correcting inaccurate thoughts and discourage negative self-talk, and by exploring the possibility of introducing alternative (more positive) thinking. The Thinking-Feeling-Doing model was introduced and the influence of thoughts on behaviour and feelings was explained. While using a Spin-of-Feelings , discussing of emotions was stimulated.

On all five items concerning the intervention goal 'positive thinking', a large majority of the children had positive outcomes. Specifically, about half of the children showed an improvement from *T*0 to *T*1 on 'I think my future looks positive', 'I worry about my disease' and 'If I have gloomy thoughts about my disease, I know what to do to feel better'. From the focus group interviews, it appeared that a lot of parents did not know whether their child used the exercises with respect to positive thinking. In addition, most parents mentioned that sharing experiences with other survivors was a positive aspect of the intervention. Some parents noticed that their child seemed more open after the intervention than before.

Discussion

Previous studies showed that the OK program can improve disease-related skills and psychosocial outcomes in children with diverse chronic diseases [8]. The objective of this study was to evaluate whether the OK program was appropriate for use among paediatric survivors of childhood cancer, after adding some cancer-specific elements (OK Onco). A cancer-specific module for adolescent survivors of childhood cancer has already been developed and implemented successfully.

The results of the descriptive pilot study indicate that OK Onco is appropriate for paediatric survivors of childhood cancer and yielded recommendations for improvement of the OK Onco program. Though some parents felt that not all disease-related skills were relevant and some children seemed to master the disease-related skills before the intervention, positive outcomes were found on many items. Remarkable improvements were found with respect to social competence and positive thinking. The parents reported that sharing emotions and experiences with other survivors of childhood cancer was an important element of the OK Onco program, which underscores the benefit of a disease-specific program for cancer survivors.

Further research is needed to establish the promising results that were found in the current, small study. The next steps would be: (1) providing a larger sample size and (2) inclusion of a control group without intervention, or an emotional support group only getting attention from the group leaders and meeting fellow patients.

The response to the invitation to take part in the intervention at the Emma Children's Hospital AMC was low (20%). The accessibility of OK Onco has to be enlarged. Successful implementation of the face-to-face course OK Onco could only be possible if the intervention is no longer limited to the Emma Children's hospital AMC. Therefore, the program will be provided to all academic medical centres for childhood cancer in the Netherlands. It is also worth to examine the possibilities of adapting OK Onco for paediatric patients with cancer who are still in cancer treatment. Furthermore, an on-line psycho-educational group intervention could be a useful way to optimalize the reach of survivors because it eliminates barriers such as time and distance. It could be open to survivors from all of the Netherlands and links up with the digital environment of children and adolescents. The standardized OK Onco is now being adapted and being made computer-accessible for adolescent survivors.

Notes

1. For some items, the opposite applies.

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